Recruiting and Retaining Hispanics in Health Research: A Narrative Review

An Honors Thesis (HONR 499)

by

Monica Del Ciello

Thesis Advisor

Dr. Jagdish Khubchandani

Ball State University

Muncie, Indiana

May 3, 2018

Expected Date of Graduation

July 2018

Abstract

Health research studies are the most effective and scientific way to find treatments or plan programs that can help prevent, treat, or cure a variety of health problems. However, these studies can only benefit the health of populations that are invited to and are willing to participate. Ethnic and racial minorities not only experience many health disparities, but are also less likely to participate in these health research studies. This study will review the results of 13 different articles that analyze methods for recruiting and retaining the Hispanic population in health research. Successful techniques include building relationships with the Hispanic community, providing sufficient information about the studies, preparing English *and* Spanish language materials, and making various other cultural considerations. While many techniques for recruiting and retaining minorities are often employed, a greater effort is still necessary to recognize and utilize the techniques that are successful particularly for the Hispanic culture.

Acknowledgements

I would like to thank Dr. Jagdish Khubchandani for guiding me through this project that will wrap-up my time at Ball State. I would also like to thank Sarah Gremer for encouraging and assisting me throughout this tough final semester and the entire department of Health Science and Nutrition for providing me the skills necessary to complete this project. Finally, I want to thank my parents for making college a possibility and Sabrina Hernandez for being a one-in-a-million roommate and best friend that I would not have survived college without.

Process Analysis Statement

To complete this literature review, I conducted three different searches on three different databases, for a total of nine searches. I then reviewed the first 100 articles yielded from each search, in order to extract the articles most pertinent to my topic. This resulted in a collection of 22 articles, which were then thoroughly read to extract information about recruiting and retaining Hispanics for participation in health research. I created an annotated bibliography to organize all the information that was gathered. Reading all of the articles and summarizing them was definitely the most intensive part of this project, due to the time and focus required. After reading through all of the articles, nine of them were eliminated from the review because they did not pertain to the topic or did not provide enough relevant information. The information from the 13 utilized articles was then organized into themes, which provided the structure for the paper. The information is organized just like any published article, with an introduction, background information, methods, results, and a discussion. This allows the reader to be able to review the entire article, or find just the information they are looking for.

Although I have completed a lot of research in my time at Ball State, this process was definitely a lot more intensive and difficult than expected. However, it was necessary in order to gather sufficient information to produce a quality piece that could potentially guide professors, researchers, or doctors. The experience also provided me with the skills and knowledge necessary to complete this type of in-depth research in the future when planning and implementing health education and promotion programs.

Introduction

From a cold or the flu, to heart disease and cancer, everyone experiences some types of health problems throughout their life. However, racial and ethnic minorities are at a much greater risk for experiencing diseases, associated complications, and premature mortality. For example, African Americans have a higher incidence rate of cancer than any other group, diabetes is more prevalent among the Hispanic population, and American Indians and Alaska Natives have higher rates of illicit drug use (US Department of Health and Human Services [HHS], 2016). In most cases, these disparities are caused by factors such as limited access to healthcare and low socioeconomic status. However, a less recognized contributing factor is the lack of evidence-based health promotion programs and disease prevention measures. For these programs and measures to be successfully developed and tested, it is necessary for minority populations to participate in the research that contributes to the formation of the programs. Ethnic and racial minorities are often not included or do not participate in health related research. Therefore, causes for illness and effectiveness of intervention programs are less well understood for these groups. Hispanics can be considered at an even greater risk for health disparities and inequalities because they may experience the added inconvenience of a language barrier, immigration complications, and other cultural factors. While some research has been done on the general lack of minority participation in research, this literature review will focus on the Hispanic population and the health disparities they experience, reasons why they are not participating in health-based research, and suggestions on how to increase participation and improve the health outcomes of this minority group.

Chapter 1: Background on the Hispanic Population in the US

As of 2015, it was estimated that 56,496,122 Hispanics lived in the United States. Of these nearly 56.5 million, 27.6% have graduated high school, while only 10.2% have received a bachelor's degree. The median household income of Hispanics is $44,782, about 60% of the population is employed, and 20% do not have health insurance (United States Census Bureau, 2015). At first glance, the health of Hispanics in the US may not seem poorer than other groups. This has to do with the concept of the "Hispanic paradox", which explores why although many Hispanics have a lower socioeconomic status, they actually have better health outcomes than non-Hispanic Whites that generally have a higher socioeconomic status (Franzini, Ribble, & Keddie, 2001). According to the United States Health Report from 2016, the life expectancy for Hispanics at birth is actually the highest of any other group in the US, with males expected to live 79.3 years and females expected to live 84.3 years. In addition, Hispanics have significantly lower morbidity and mortality rates for the top five causes of death in the US than their non-Hispanic White counterparts (Murphy, Xu, Kochanek, Curtin, & Arias, 2017). However, there are still some areas in which Hispanic health disparities are noticeable. One of the greatest health disparities experienced by this group is in the prevalence of diabetes. Between 2011 and 2014, 18% of those of Mexican origin who lived in the US had diabetes, whereas only 9.6% of the White, non-Hispanic population suffered from it (HHS, 2016). In addition, when compared to their non-Hispanic White counterparts, Hispanics are 24% more likely to have poor blood pressure control, 23% more likely to be obese, and 28% less likely to receive colorectal screenings, demonstrating disparities in regard to disease prevalence and risk factors, as well as access to and knowledge about screenings and prevention methods (Centers for Disease Control and Prevention [CDC], 2015). Tables 1 outlines the top ten causes of death for Hispanics.

Increasing Hispanic recruitment and retention in health research studies can aid the further exploration of the Hispanic paradox, as well as the reduction of pertinent health problems such as diabetes, and the increase in access to and use of resources, services, and knowledge.

Table 1
Top Leading Causes of Death in Hispanics

Rank	Cause of Death
1	Cancer
2	Heart Disease
3	Unintentional Injuries
4	Stroke
5	Diabetes
6	Chronic Liver Disease/Cirrhosis
7	Chronic Lower Respiratory Disease
8	Alzheimer's Disease
9	Influenza and Pneumonia
10	Kidney Diseases

(CDC, 2015)

Chapter 2: Participation of Minorities in Health Research

Various factors contribute to the under-representation of minorities in health research studies. One reason why minorities are not widely represented in health research studies may be that they simply do not want to participate. This may be due to factors such as distrust, lack of interest, or lack of knowledge about the study. As discovered in Benjamin Bates' and Tina Harris' focus group study from 2004, one example of a source of some of these factors is the Tuskegee Syphilis Study, which studied 600 African American men in order to support treatment programs for syphilis. The study was conducted without an informed consent process, and most participants were not informed if they had the disease, nor were they provided proper treatment. The study began in 1932 and ended in 1972, when it was deemed unethical (CDC, 2017). Although not directly associated with the Hispanic population, this infamous case does impact how minorities perceive health research, because it causes suspicion of studies, mistrust of doctors and researchers, and leads to minorities ultimately not wanting to participate in health research (Bates & Harris, 2004). However, another study found that it might not necessarily be the will of the minorities that is affecting their participation. This study analyzed various other health research studies to determine the consent rate of minorities in comparison to that of non-Hispanic Whites. In the comparison of 20 different studies, it was actually found that the consent rate of Hispanics to participate was regularly higher, if not similar, to that of non-Hispanic Whites. For example, a schizophrenia drug maintenance trial held in 1994 had 47.9% of Hispanics that were offered enrollment agree to participate, but only 37.2% of non-Hispanic Whites agreed. However, 611 Whites were offered enrollment, while only 94 Hispanics were invited to participate (Wendler et al., 2005). Ultimately, enrollment in the study was offered to and accepted by significantly more non-Hispanic Whites than Hispanics, demonstrating the

discrepancy in recruitment numbers between the two groups. This introduces a second possibility for low minority research participation-that minorities are not being efficiently recruited to participate in these studies.

To combat recruitment discrepancies such as these, the National Institutes of Health developed the NIH Revitalization Act of 1993, which provides guidelines for ensuring adequate recruitment and fair treatment of women and minorities in all NIH-funded studies (National Institutes of Health [NIH], 2001). These guidelines are summarized in the following policy:

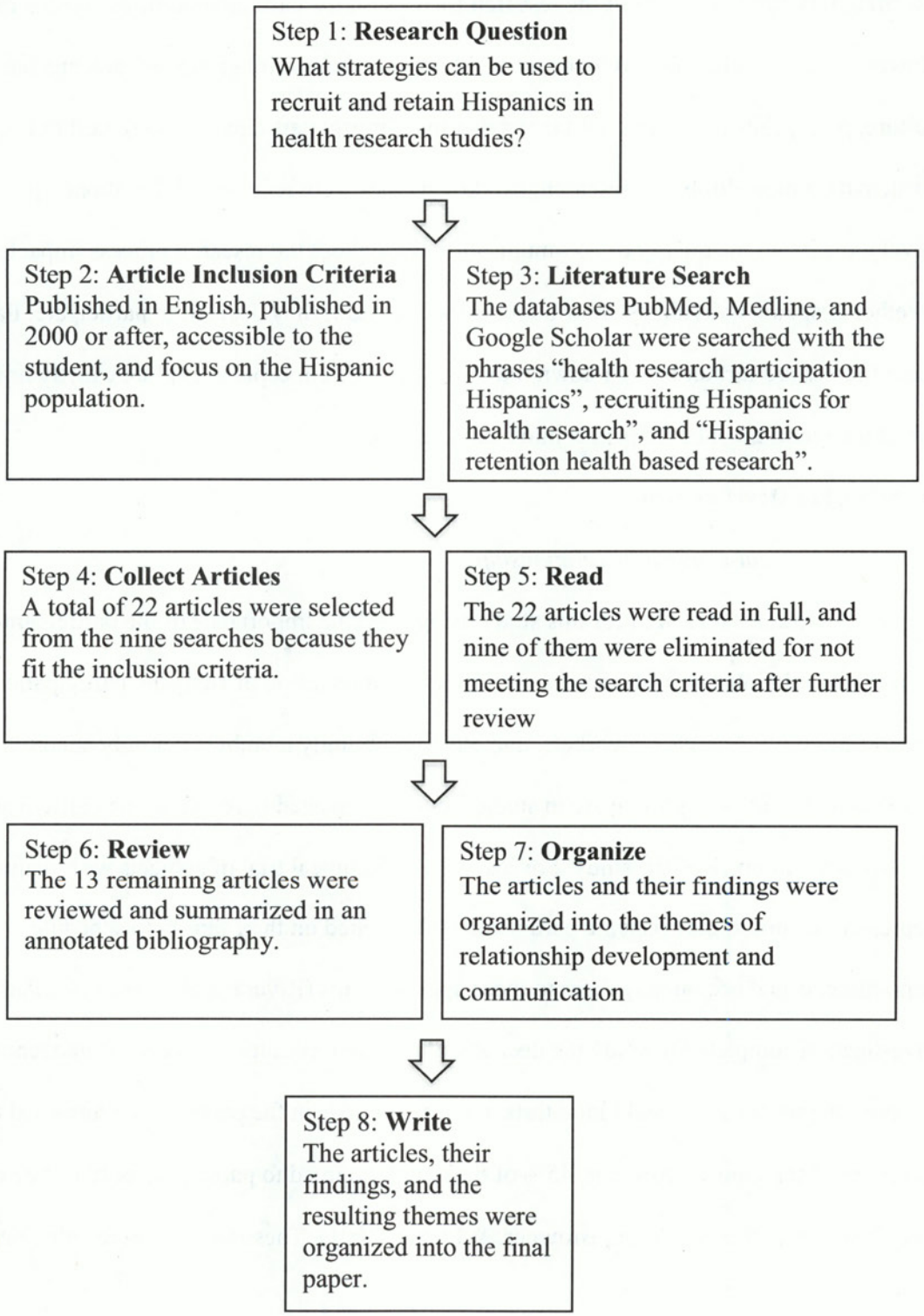
"It is the policy of NIH that women and members of minority groups and their subpopulations must be included in all NIH-funded clinical research, unless a clear and compelling rationale and justification establishes to the satisfaction of the relevant Institute/Center Director that inclusion is inappropriate with respect to the health of the subjects or the purpose of the research. Exclusion under other circumstances may be made by the Director, NIH, upon the recommendation of an Institute/Center Director based on a compelling rationale and justification. Cost is not an acceptable reason for exclusion except when the study would duplicate data from other sources. Women of childbearing potential should not be routinely excluded from participation in clinical research. This policy applies to research subjects of all ages in all NIH-supported clinical research studies. The inclusion of women and members of minority groups and their subpopulations must be addressed in developing a research design or contract proposal appropriate to the scientific objectives of the study/contract. The research plan/proposal should describe the composition of the proposed study population in terms of sex/gender and racial/ethnic group, and provide a rationale for selection of such subjects. Such a plan/proposal should contain a description of the proposed outreach programs for recruiting women and minorities as participants" (NIH, 2001).

Despite increasing awareness of the low participation rates of minorities in health research and the guidelines to combat such disparities, there is still a need for more research on the topic in regard to specific minority populations. While many studies address the general issue of minority participation in health research studies, it is necessary to conduct research that focuses on each specific culture, in order to understand and utilize specialized recruitment and retention techniques. Therefore, this study aims to explore and analyze Hispanic individuals' research participation and summarize the best methods for recruiting and retaining Hispanic populations in health research studies, in order to increase their participation and ultimately improve health outcomes.

Chapter 3: Methods

This review consisted of three different searches completed on the databases PubMed, Medline, and Google Scholar. Criteria for inclusion in this review was that the study focused on the Hispanic population, articles were published in English and were accessible to the student, and the study was published in 2000 or after. The term "Latino" was intentionally not used in the searches, in order to avoid locating articles with this term rather than "Hispanic". However, any articles that did use the term "Latino" were still utilized in this study, to account for any authors that may have used the term as a synonym for "Hispanic". "Latino" refers to anyone from a Latin descent (countries such as Spain, Portugal, or France), while the term "Hispanic" refers to anyone from a Spanish descent (only from Spain). This study puts value on which term was used in other studies, as recruitment and retention techniques could potentially vary between Hispanics and Latinos, especially in the language used. The first 100 results from each database were reviewed for appropriate articles. The first search was "health research participation Hispanics", which yielded 854 results on PubMed, 7,725 results on Medline, and 397,000 results on Google Scholar. Nine of these results were included for further review. The second search was "recruiting Hispanics for health research", which yielded 109 results on PubMed, 7,692 results on Medline, and 63,000 results on Google Scholar. Seven of these results were included for further review. The final search was "Hispanic retention health based research", which yielded 120 results on PubMed, 35,137 results on Medline, and 175,000 results on Google Scholar. Six unique articles from this search were included for further review. A total of 22 articles were considered for this study. Each of the articles was read and summarized in an annotated bibliography format. After more thorough review, nine of the 22 chosen articles were eliminated from the study because they did not address the desired topic or did not provide

sufficient information on Hispanic recruitment and retention tactics. Ultimately, 13 articles were considered in this review. The following chart outlines the research process.



Chapter 4: Results

After searching for articles that specifically discuss Hispanic participation in health-based research, it is clear that most of the research focuses on the participation of minorities in general. However, more studies should focus on each individual minority group, as each one has its own culture, perceptions, and personal factors that may impact participation. In regard to Hispanic participation in health-based research, two key themes were recognized. Relationship development and the quality of communication throughout the research process impacted whether Hispanic individuals knew about the study and if they decided to participate. Each of these themes are further broken down into more detailed concepts to explore exactly how they affect the recruitment of Hispanics into health research.

Relationship Development

Participant-community relationship

All articles reviewed for this study recognized the importance of the participant-community relationship in successful recruitment and retention of Hispanic participants. The support of family, friends, coworkers, and other community members not only encouraged Hispanic individuals to participate in studies, but also assisted in retaining the participants throughout the course of the study. For instance, in a clinical trial of subjects with major depressive disorder, the Hispanic participants often relied on their family to schedule appointments and accompany them to those appointments (Rivera et al., 2013). Similarly, in an investigation completed to study the decision of Hispanic couples to receive amniocentesis after a report of abnormal prenatal blood tests, both individuals in the couple were supposed to be interviewed separately. However, 45% of the couples agreed to participate only if they could be interviewed together (Preloran, Browner, & Lieber, 2001). These two examples illustrate how

important the concept of family is to the Hispanic population and how it can influence their decision to participate and remain in research studies. Yet another important relationship to recognize when recruiting Hispanics for participation in health research is the relationship they have with community members. Multiple studies utilized community engagement strategies, such as small community based events, to build relationships with stakeholders in the Hispanic community (De La Rosa, Babino, Rosario, Martinez, & Aijaz, 2012; Eakin et al., 2007; Larson, Ferng, Wong-McLoughlin, & Wang, 2009). These stakeholders could then help effectively recruit Hispanic individuals to participate in a research study because they are trusted and respected members of the community. In fact, in some studies, this was the only effective recruitment method (García, Zuñiga, & Lagon, 2017). In some cases, this method also lead to the use of "snowball sampling", where knowledgeable community members would recruit three or four eligible individuals, who would go on to recruit three or four more, and so on and so forth (De La Rosa et al., 2012; García et al., 2017). Another important group that is often recognized in Hispanic communities is religious figures. Due to the sensitive information involved in a HIV/AIDS study, one woman went to her pastor to ask if she should participate, and once he gave her permission, she agreed to be involved (Shedlin, Decena, Mangadu, & Martinez, 2011). Other community members that Hispanic individuals report relying on for information and assistance include coworkers and other individuals from their country of origin (Shedlin et al., 2011). Similarly, it is clear that it is also important to consider the concept of a researcher-community relationship. Most, if not all, studies utilize this method to gain access to the community, establish trust in potential participants, and maintain participant interest in the study. One great demonstration of this researcher-community relationship is seen in a study that recruited Hispanic high school students for research exploring risky sexual behaviors. The

researchers met with school administration not only to discuss the details of the study and its benefits, but also to see how they could help the school and how they could recruit so as to minimally intrude on class time (Villaruel, Jemmott, Jemmott, & Eakin, 2006). Efforts such as these show that researchers are not only concerned with their own work, but also with the good of the community that they are in.

Researcher-participant relationship

In order to encourage Hispanics to take part in research studies, and once those eligible Hispanic individuals agree to participate in health-based research, it is very important for the researcher to develop a comfortable and trustful relationship with potential participants. This may involve approaching potential participants with a friendly demeanor, being available to answer any questions or attend to concerns, and giving the participants some control over the environment. First of all, a kind, personable demeanor can be what initially interests Hispanic individuals in research opportunities, and what ultimately encourages them to decide to participate. This was shown in a 2001 study about pregnant Hispanic couples' decision to receive a procedure that would collect a sample of amniotic fluid. The majority of the recruitment for this study was done at the doctor's office, right after the women (or couples) received the news that they had an abnormal prenatal blood test. Therefore, researchers approached the women carefully. For example, researchers made conversation, offered to watch the women's children or to help with paperwork, and also listened to any complaints or concerns they had about their appointment. This way, the women felt that they already had a personal connection with the researcher when the study was brought up. While this tactic could be seen as misleading and unfair, it was determined that for this particular study, the researchers approached the situation in a way that there would be no misconceptions about who they were (Preloran et al., 2001). In

addition, being provided adequate information about the study, including its expectations, risks, side effects, and costs, has been recognized as a reason that Hispanic individuals would be more likely to participate in a health-based research study (Arevalo et al., 2016). This is connected to the theme of researcher-participant relationships because the researcher can provide all this information, which can lead to more Hispanic participants engaging in studies, as well as a pre-established sense of trust. In fact, in some studies, researchers take the time to go through extensive, pre-recruitment preparation programs that train staff to work with the Hispanic population, attend to any questions or concerns, and handle any unexpected circumstances (De La Rosa et al., 2012). A final successful recruitment and retention tactic was when researchers assured Hispanic participants (especially the males) that they could have some control over the experience. To encourage men to participate in the study about amniocentesis with their partner, researchers reminded them that they could always vocalize their thoughts and concerns, refuse to answer any questions, or drop-out from the study at any time. Despite being given the option to drop-out, retention rates for this study were very high, with only one man and two couples leaving the study before it was completed (Preloran et al., 2001). A similar tactic was also used for a study about HIV/AIDS in the Hispanic community, where the participants were allowed to choose where they wanted their interview to take place (Shedlin et al., 2011). A final important aspect when considering researchers' relationship with their Hispanic participants is the Hispanic origin of the researcher. Although not a strategy that has been utilized in all studies, some Hispanics have reported that they would be more likely to participate if they were recruited by Hispanic staff (Arevalo et al., 2016). While this is often just because it makes the Hispanic participants feel more comfortable, this desire is also occasionally caused by Hispanics' perceptions that non-Hispanic doctors and researchers have prejudicial thoughts towards and

discriminate against them (Ellington, Wahab, Sahami, Field, & Mooney, 2003). There are many aspects of the researcher-participant relationship that are vital to improving recruitment and retention for health research.

Participant-physician relationship

While not necessarily within control of the researchers, it was also recognized in some studies how the relationship that a potential research participant has with their doctor can affect their decision to participate. One study reviewed what Hispanic individuals know about cancer randomized clinical trials (RTCs) and what factors impact their decision to participate in them. Along with adequate communication and knowledge, most participants viewed the development of a personal relationship with their physician as "essential" to deciding whether to participate, because they wanted to be able to discuss every aspect of the trial with someone they trusted on the subject. However, many Hispanics also wonder if doctors in the US actually value this type of relationship, because they do not seem to dedicate a lot of time to their patients (Ellington et al., 2003). Interestingly, through Redes en Acción, a program developed in response to requests for more research about health disparities among minority populations, 2000 physicians across the nation were surveyed to find out what they understood their Hispanic cancer patients' health problems and needs are. While Hispanic and non-Hispanic White physicians generally agree upon the most important cancer sites in Hispanics (breast, lung, and cervix being the top three), there are some discrepancies in what are the most important cancer issues. Out of fifteen issues, Latino physicians believe poor nutrition is the fourth most important factor contributing to cancer in Hispanics, but non-Hispanic White physicians view poor nutrition only as the seventh most relevant issue. In addition, Latino physicians view clinical trial participation as the thirteenth most important problem contributing to cancer, while non-Hispanic White physicians

view this as the least important issue (Ramirez et al., 2006). While clinical trial participation will not necessarily prevent or treat cancer, it is an important factor in researchers and doctors better understanding how cancer affects this population. These discrepancies suggests that there is not currently sufficient communication between physicians and their patients, and that increasing communication could improve the understanding that doctors have of Hispanic health, as well as the participation of Hispanics in health research studies.

Communication

Language and Incentives

When we consider the factor of language in recruiting Hispanic individuals to participate in health-based research, we often focus on materials and information being provided in English and Spanish. While this is important, we must also consider the impact that Hispanic individuals' level of education and perception of vocabulary can impact recruitment and retention rates. For example, one clinical trial of subjects with major depressive disorder found that although they provided all of their materials in English and Spanish, the Spanish-speaking participants still had a difficult time understanding all of the information (Rivera et al., 2013). Another study which strove to inform policy and program planning for HIV/AIDS in a Hispanic community found that the words researchers used when speaking to Hispanic participants were also important. For example, words such as "study", "conversation", and "dialogue" were preferred over words like "investigation", "research", and "interview" because they were less threatening. Similarly, Hispanic participants also found it more comfortable when they were described as "students", and the researchers as "teachers" (Shedlin et al., 2011). These factors of communication impact not only how comfortable Hispanic individuals would be participating and remaining in a study, but also if they feel they know and understand enough to provide informed consent.

Another interesting aspect of communication is the incentives that are offered to participants. While offering incentives for participation in a research study can generally be agreed upon as beneficial to recruitment, there seem to be mixed reactions in regard to what type of incentives should be offered in the studies reviewed. For example, a monetary incentive may suggest that the researchers think the participant is poor, and providing health services as an incentive may suggest that the researchers do not think the participants have health insurance. Some Hispanic participants have stated that they would like to receive a monetary incentive, while others reported that they would not accept money for participation (Arevalo et al., 2016). In fact, Hispanic individuals are more motivated to participate in health research based on recruitment through the church and the opportunity to help the community, rather than other incentives (Haack, Gerdes, & Lawton, 2014). In most cases, those unwilling to accept money were Hispanic men who were either "too proud" to accept the money, or only wanted to participate in the research for the good of their community (Preloran et al., 2001; Shedlin et al., 2011). Other suggestions for incentives included waived medical fees, transportation, refreshments, and child care (Arevalo et al., 2016). Considering language, vocabulary, and values is not only necessary for determining appropriate participation incentives, but also for effectively recruiting and retaining Hispanic participants.

Knowledge

It is also very important that potential Hispanic research participants are provided all of the information about the study that they can get, in order to trust the process and feel comfortable in participating. In some cases, it may even be necessary to educate participants about research and clinical trials in general, before focusing on the details of the particular study. A study was completed in Texas to see how Mexican-Americans perceive clinical trials, and it

was found that many of these participants had a very limited or incorrect understanding of clinical trials. For example, one participant shared that she thought a clinical trial is when a doctor sends you to get lab work done (Arevalo et al., 2016). Another study about decision-making factors in regard to Hispanics' participation in cancer randomized clinical trials (RCTs) also found that only the highly educated participants understood the concept of RCTs, and that the less educated viewed them as "scary" and "aggressive" forms of treatment (Ellington et al., 2003). In a final study, participants were provided with business cards so they could contact the researcher with any questions or concerns; however, many of these participants thought the cards were a ticket that allowed entry into the study, rather than a way to contact the researchers (García et al., 2017). Therefore, thoroughly educating Hispanic participants about the research process could potentially help alleviate some of the associated confusions and fears such as being used as guinea pigs, experiencing negative side effects, and problems with immigration status (Arevalo et al., 2016). Some practiced and successful techniques for thoroughly informing this population about health-based research studies include discussion, brochures, and addressing the fears or questions of the participant. For instance, researchers in a HIV prevention study in a high school spent sufficient time prior to recruitment educating the administration and students on the research process, and another series of studies utilized English and Spanish language flyers and brochures to disseminate study information, in case potential participants would be uncomfortable discussing their questions and concerns with the research staff (Villarruel et al., 2006; García et al., 2017). While it is important for the researcher to relay information that they find important about the study, it is also important to address any questions or concerns the participants may have. For instance, a study that explored substance use and HIV-risk behaviors in the recent Hispanic immigrant population incurred problems with the sensitive nature of the

topic and with participants believing that the researchers might be from the government. This problem was resolved by maintaining open communication, establishing trust, and allowing the participants to choose where interviews were held (De La Rosa et al., 2012).

Maintaining contact

Constant communication is an important factor in the retention of Hispanic participants in health research. However, this can be difficult in some cases due to participants moving, going on vacation, or changing their phone numbers. This problem can be addressed by initially collecting alternate phone numbers or email addresses where the participants can be reached (Eakin et al., 2007). However, maintaining contact and continuing to reach out and inform participants is not the only way to maintain their interest and participation in the study. Other retention techniques have included sending birthday or holiday cards to participants to demonstrate interest and concern for the participants at a personal level, rather than solely in regard to the research (Villaruel et al., 2006). However, maintaining contact does not only mean that the participant should be able to be reached at all times. It also means that the researcher is ensuring open communication between themselves and the participant. In multiple cases, Hispanic individuals view a benefit of participating in health research as being able to talk about their health and experiences in the study with their doctor and/or the researcher (Ellington et al., 2003; Shedlin et al., 2011). Therefore, it is important that researchers remind participants that they can talk to them, and ensure that they are providing them with all pertinent information in regard to the study or any health related concerns and issues. Maintaining contact is a method unique to retention, because all other methods tend to overlap with those used for recruitment.

Chapter 5: Discussion

This chapter summarizes the results of Chapter 4. Specifically, Table 2 summarizes the strategies discussed in this study that have proven successful in the recruitment and retention of Hispanic research participants. Multiple techniques (community support, building personal relationships, addressing fears and questions, and physician-patient communication) are listed as both recruitment and retention strategies because it is essential that they are utilized throughout the entirety of the study.

Table 2
Effective Strategies for Recruiting and Retaining Hispanics in Health Research

	Recruitment	Retention
Intrapersonal	• Participants' knowledge about study • Participants' fears and questions • Researcher cultural competence • Creating Spanish & English materials • Using "preferred" vocabulary and an appropriate reading level	• Interest in study • Trust of researcher • Attending to participants' fears and questions • Conducting needs assessments • Collect multiple forms of contact information • Frequent follow-ups
Interpersonal	• Community support (friends, family, coworkers, religious figures) • Snowball sampling • Personal relationships • Physician-patient communication • Providing adequate information • Ensuring privacy	• Community support (friends, family, coworkers, religious figures) • Accompaniment to meetings/appointments • Sharing control in study • Maintaining thorough communication • Communication beyond research (birthdays, holidays)
Societal	• Recruiting in the community	• Offering child care/transportation services

These findings can be compared and contrasted with the findings of another study that explored techniques for increasing the recruitment and retention of diverse participants in health education research. This 2016 study which gathered information about all minority groups also recognized the importance of snowball sampling, recruiting through the community, maintaining constant communication, building trust, providing cultural competence training, considering language and reading level, constantly following-up, and ensuring privacy (Khubchandani, Balls-Berry, Price, & Webb, 2016). These concepts that apply to minorities in general overlap with the concepts that were recognized in this study as effective for the Hispanic population in particular. However, this same study also lists some strategies that were not necessarily recognized as effective in this study on the Hispanic population. These include recruiting through social media, consideration of the age and gender of the researcher, providing incentives, having members of the target audience on the research team, and the presentation or appearance of the researcher (Khubchandani et al., 2016). This shows that although there is some overlap in what is considered an effective strategy for recruiting minorities, there are certain techniques that do not work for some groups, as well as some techniques that are pertinent only to certain cultures.

Hispanics, African-Americans, American Indians, and Pacific Islanders cannot all be recruited and retained through the same tactics because "minority" is not a culture. However, each minority group does have their own culture that should be considered and utilized for the research process. For example, for Hispanics, the concepts of confianza, respeto, familismo, and machismo are all very important and strictly followed (García et al., 2017). Confianza describes the value of trust and respeto relays the value of respect, while familismo is the idea that family is what is most important and should be heavily involved in one another's lives, and machismo is the idea that the men in the family are strong, tough, and in charge. These values are obvious in

the recruitment and retention methods that have proven successful, such as maintaining open-communication with the participant throughout the research process, listening and attending to participants' concerns and desires, including family members in the recruitment and research process, and giving men control over the situation they are in (García et al., 2017; Preloran et al., 2001).

After analyzing the few studies that have consciously attempted to increase Hispanic participation, there are some clear recommendations that can be made. From community engagement, to relationship building, and sufficient preparation, there are various factors that can lead to successful recruitment of Hispanics for participation in health research. Many studies recommend sufficient preparation periods prior to recruitment, in order to build community relationships and test materials (Eakin et al., 2007; Tenorio et al., 2014). For example, a randomized clinical trial to test a physical activity and diet intervention spent about a year prior to recruitment building relationships within the community, translating materials, and hiring and educating bilingual staff. A major aspect of this pre-recruitment phase involved cultural competence training, so that staff could better understand the Hispanic culture and apply it to their recruitment and retention efforts (Eakin et al., 2007). In other cases, this period was also used to pilot test materials, in order to ensure that language translations were correct and an appropriate reading level was used. It is also necessary to consider the literacy and education levels of potential Hispanic participants. In preparation for a lung cancer research study, it was realized that no materials above a fifth-grade reading level would be understood by most participants, therefore, recruitment forms and information had to be edited before the process could begin (Tenorio et al., 2014).

There are also suggestions that can be made in regard to future research. First of all, it is necessary that more studies be conducted which explore recruitment and retention techniques for each minority group, rather than the minority population as a whole. This will help with the realization, understanding, and implementation of unique tactics that will lead to successful recruitment of these groups. Another suggestion is to fund and develop more programs that focus on the recruitment of minorities as a method for decreasing health disparities. For example, Redes en Acción was established in 2000 after the National Cancer Institute requested that more minorities be included in cancer research. This program in particular networked with the National Hispanic Medical Association, the Susan G. Komen Breast Cancer Foundation, and other organizations that could help propel funding, research, and education efforts that would result in the recruitment and participation of more Hispanics (Ramirez et al., 2006). Larger programs such as these are necessary to help decrease and potentially eliminate the disparities that exist in health outcomes and research participation among the Hispanic population.

Ultimately, the principles of beneficence, justice, and respect should guide the processes of recruiting and retaining Hispanic participants for health research. One way of treating all ethnic and racial groups equally is through providing everyone an opportunity to participate in health research, which can help prevent disease and decrease disparities (Yancey, Ortega, & Kumanyika, 2006). To reach this standard, it is necessary to respect each culture, and raise awareness of the values and morals that guide their life and decision to participate in health research studies. This can be done through a variety of methods that can be used to recruit and retain the Hispanic population in health research. Thorough preparation should be done prior to recruitment which involves training staff, developing English and Spanish materials, and building relationships in the community. Recruitment should be done through stakeholders in the

community, especially with the key figures of the church. Forming relationships with the family and friends of potential participants is also vital because they can encourage the individual to participate and remain in the study. In the recruitment phase, thorough research and needs assessments should also be completed to evaluate whether or not the participants expect incentives, and what they would want those incentives to be (Arevalo et al., 2016). In order to retain Hispanic participants throughout the entirety of a study, it is necessary to maintain open communication, address the participants' concerns, and allow them to have some control over the research process. Alternate contact information for the participants should also be collected so that they can always be reached. If these culture-specific tactics are employed and further research is completed about how to recruit and retain Hispanic individuals in health research, appropriate programs can be planned and implemented to decrease the health disparities that exist among this population.

Limitations

Despite the depth of the research, there are still some factors that limit the study and its results. For instance, only three different searches across three different databases were completed, which may have limited the number of articles that were found on the topic. Similarly, as a student, not all articles that were yielded from the searches could be accessed, therefore not all studies on the topic could be accounted for. In addition, avoiding the use of the term "Latino" in the searches may have also limited results (refer to the "methods" section for why this term was not used).There are also limitations involved with completing a literature review rather than conducting a qualitative or quantitative study. This type of study relies on data that has already been collected, which could be outdated, and may not address all factors that contribute to the recruitment and retention of Hispanics in health research.

References

Arevalo, M., Heredia, N. I., Krasney, S., Rangel, M. L., Gatus, L. A., McNeill, L. H., & Fernandez, M. E. (2016). Mexican-American perspectives on participation in clinical trials: A qualitative study. *Contemporary Clinical Trials Communications*, 52-57. doi: 10.1016/j.conctc.2016.06.009

Bates, B. R. & Harris, T. M. (2004). The Tuskegee study of untreated syphilis and public perceptions of biomedical research: A focus group study. *Journal of the National Medical Association, 96*(8), 1051-1064.

Centers for Disease Control and Prevention. (2015). Hispanic health. Retrieved from https://www.cdc.gov/vitalsigns/hispanic-health/index.html

Centers for Disease Control and Prevention. (2017). U.S. public health service syphilis study at Tuskegee. Retrieved from https://www.cdc.gov/tuskegee/index.html

De La Rosa, M., Babino, R., Rosario, A., Martinez, N. V., Aijaz, L. (2012). Challenges and strategies in recruiting, interviewing, and retaining recent Latino immigrants in substance abuse and HIV epidemiologic studies. *The American Journal on Addictions, 21*(1), 11-22. doi: 10.1111/j.1521-0391.2011.00193.x

Eakin, E. G., Bull, S. S., Riley, K., Reeves, M. M., Gutierrez, S., & McLaughlin, P. (2007). Recruitment and retention of Latinos in a primary-care based physical activity and diet trial: The resources for health study. *Health Education Research, 22*(3), 361-371. doi: 10.1093/her/cyl095

Ellington, L., Wahab, S., Sahami, S., Field, R., & Mooney, K. (2003). Decision-making issues for randomized clinical trial participation among Hispanics. *Cancer Control, 10*(5), 84-86. doi: 10.1177/107327480301005s12

Franzini, L., Ribble, J. C., & Keddie, A. M. (2001) Understanding the Hispanic paradox. *Ethnicity and disease, 11*(3), 496-519.

García, A. A., Zuñiga, J. A., & Lagon, C. (2017). A personal touch: The most important strategy for recruiting Latino research participants. *Journal of Transcultural Nursing, 28*(4), 342-247. doi: 10.1177/1043659616644958

Haack, L. M., Gerdes, A. C., & Lawton, K. E. (2014). Conducting research with Latino families: Examination of strategies to improve recruitment, retention, and satisfaction with an at-risk and underserved population. *Journal of Child and Family Studies, 23*(2), 410-421.

Khubchandani, J., Balls-Berry, J., Price, J. H., & Webb, F. J. (2016). Community-engaged strategies to increase diversity of participants in health education research. *Health Promotion Practice, 17*(3), 323-327. doi: 10.1177/1524839916644713

Larson, E. L., Ferng, Y., Wong-McLoughlin, J., & Wang, S. (2009). Retention a protocol adherence of Hispanic volunteers in a longitudinal trial. *American Journal of Health Behavior, 33*(4), 435-444. doi: 10.5993/AJHB.33.4.9

Murphy, S. L., Xu, J., Kochanek, K. D., Curtin, S. C., & Arias, E. (2017). Deaths: Final data for 2015. *National Vital Statistics Reports, 66*(6), 1-73. Retrieved from https://www.cdc.gov/nchs/data/nvsr/nvsr66/nvsr66_06.pdf

National Institutes of Health. (2001). NIH policy and guidelines on the inclusion of women and minorities as subjects in clinical research. Retrieved from https://grants.nih.gov/grants/funding/women_min/guidelines.htm

Preloran, H. M., Browner, C. H., & Lieber, E. (2001). Strategies for motivating Latino couples' participation in qualitative health research and their effects on sample construction. *American Public Health Association, 91*(11), 1832-1841.

Ramirez, A. G., Talavera, G. A., Marti, J., Penedo, F. J., Medrano, M. A., Giachello, A. L., & Pérez-Stable, E. J. (2006). Redes an acción. Increasing Hispanic participation in cancer research, training, and awareness. *Cancer, 107*(8). doi: 10.1002/cncr.22148

Rivera, V. A., Dunlop, B. W., Ramirez, C., Kelley, M. E., Schneider, R., Blastos, B.,...Craighead, W. E. (2013). Enhancing Hispanic participation in mental health clinic research: Development of a Spanish-speaking depression research site. *Depress Anxiety, 31*(3), 258-267. doi: 10.1002/da.22153

Shedlin, M. G., Decena, C. U., Mangadu, T., & Martinez, A. (2011). Research participant recruitment in hispanic communities: Lessons learned. *Journal of Immigrant and Minority Health, 13*, 352-360. doi: 10.1007/s10903-009-9292-1

Tenorio, S. L., O'Donnell, C. I., Hernandez, J., Rozjabek, H. M., Lynch, D., & Marcus, P. M. (2014). Culturally sensitive approaches to recruitment and retention of Hispanics in the national lung screening trial. *Journal of Immigrant and Minority Health, 16*, 761-764. doi: 10.1007/s10903-013-9862-0

United States Census Bureau. (2015). 2015 American community survey 1-year estimates. Retrieved from https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk

U.S. Department of Health and Human Services. (2016). Health United States Report. Retrieved from https://www.cdc.gov/nchs/data/hus/hus16.pdf

Villarruel, A. M., Jemmott, L. S., Jemmott, J. B., & Eakin, B. L. (2006). Recruitment and retention of Latino adolescents to a research study: Lessons learned from a randomized clinical trial. *Journal for Specialists in Pediatric Nursing, 11*(4), 244-250.

Wendler, D., Kington, R., Madans, J., Van Wye, G., Christ-Schmidt, H., Pratt, L. A.,...Emanuel, E. (2005). Are racial and ethnic minorities less likely to participate in health research? *PLOS Medicine, 3*(2). doi: 10.1371/journal.pmed.0030019

Yancey, A. K., Ortega, A. N., & Kumanyika, S.K. (2006). Effective recruitment and retention of minority research participants. *Annual Review of Public Health, 27*, 1-28. doi: 10.1146/annurev.publhealth.27.021405.102113